



November 16, 2010

## **Testimony to the Health Care Reform Implementation Council**

Thank you for the opportunity to present testimony today before the Council. My name is Tony Paulauski. I am the Executive Director of The Arc of Illinois. We are an advocacy organization for individuals with developmental disabilities and their families. We have about 10,000 individual members and 60 local chapters across the state.

First let me state that The Arc is a strong proponent of the Affordable Health Care Act and the positive impact it will have on the lives of 220,000 infants, children and adults who have developmental disabilities in Illinois. The elimination of lifetime caps, pre-existing conditions and discrimination based on health status are all huge victories for our families. The Arc of Illinois looks forward to working with you in the implementation of real health care reform in Illinois.

To the issues:

- 1. After January 1, 2014, the Affordable Care Act (ACA) will make about 700,000 more Illinoisans eligible for Medicaid by covering all people with incomes less than 133% of the Federal Poverty Level (now about \$14,000 for an individual or \$30,000 for a family of 4), with 100% federal funding for the first four years. What are the implications of this significant expansion for the Medicaid Program? Within the bounds of the State's fiscal condition, what changes would improve the Medicaid Program?**

This is extremely important to youth and adults with high-incidence disabilities who have gone through school with an Individual Education Plan (IEP) but have not been determined to be "disabled" by the Social Security Administration and, therefore, do not qualify for Medicaid. It also applies to young adults who have aged out of "All Kids" at 19 and are without health insurance because they are less likely to be employed full time and unable to afford ICHP.

One of the problems is that we do not collect good data here in Illinois about how many "low-income childless adults" are really out there.

Recommendations that we would make include:

- a. HFS needs to identify all children insured by All Kids who have IEP's or 504 plans and do targeted outreach to those who are not eligible for AABD before their 19<sup>th</sup> birthday. These young adults should be enrolled into the "new Medicaid for adults" here in Illinois.

- b. Part of the transition process for youth exiting school with IEP's would call for documenting their health insurance status with annual updating.
- c. Any youth who does not have or may be losing insurance coverage needs to be referred to an enrollment agent to get connected to a health plan.
- d. Community mental health agencies should be target sites for enrollment of uninsured adults previously ineligible for Medicaid.
- e. Human service/social service departments in municipalities and townships should also be target sites.
- f. Adults who apply for Supplemental Security Income (SSI) but are rejected should be automatically invited to enroll in the new Medicaid coverage.

**2. These low-income individuals and families will likely move, from one year to the next, between public coverage through Medicaid and private health insurance supported with tax subsidies through the Health Insurance Exchange. How should we ensure continuity of health care – in benefit coverage and in provider networks?**

- a. We are not sure this is a valid assumption.
- b. Our experience has been that people have fluctuating coverage based upon their employment status and they move on and off the public rolls frequently.
- c. Build upon the existing All Kids enrollment agent capacity rather than expanding enrollment responsibilities to the local DHS offices.
- d. Be sure that enrollment procedures are consumer friendly. We must take into account literacy and language needs as well as special needs including intellectual disabilities and/or behavioral health issues.
- e. See above recommendations.

**3. The ACA focuses on care management as a central theme of health care reform, with the goal of bringing together primary care physicians, specialists, hospitals, long-term care and social service providers to organize care around the needs of the patient to achieve improvements in health. How should the State incorporate the integration of medical services into Medicaid?**

- a. Within the Developmental Disabilities system we should contract with the Individual Service Coordination organizations throughout the state to integrate direct care services/supports with Medicaid medical services.
- b. Increase Medicaid rates to Medicare rates.
- c. We need strong continuity of care provisions for both in-patient and out-patient care.
- d. We need to reinstate the Office of the Ombudsperson.
- e. The current system is lacking transparency.
- f. There needs to be a better data tracking system.

- g. We need a strong quality assurance system within health care reform.
- h. See above recommendations.

**4. The ACA emphasizes home and community-based services to reduce the reliance on institutionalization for seniors and persons with special needs and offers new state-plan options for states to cover these services. What changes should be made in Illinois' long term care services system (both institutional and community-based) to improve the quality of care and achieve the most cost-effective delivery of appropriate care to achieve the best outcomes for these complex cases?**

Services to individuals with developmental disabilities have had numerous national experts review and make recommendations on the developmental disability service system. I can identify eight reports within the last ten years. All of the reports indicate that Illinois ineffectively invests in institutional care rather than community-based care. Our system ranks 51<sup>st</sup> in the small community living opportunities; 47<sup>th</sup> in spending on community services and 5<sup>th</sup> on spending on state institutions. Clearly our system is upside down and needs to be rebalanced by investing in community-based services/supports and money follows the individual models.

The "Blueprint for System Redesign in Illinois" is an excellent roadmap for rebalancing this institutional system to a community-based system over a seven year period.

Lastly, while The Arc embraces health care reform as we transition to a full community-based system, we need to increase the rates we pay to community providers to cover the cost of health care reform in Illinois.

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